HIV Mental Health for the 21st Century

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Published by NYU Press

Winiarski, Mark G.
HIV Mental Health for the 21st Century.
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HIV disease has come to small-town and rural America. It may be less visible because of the relatively thin spread of cases over larger geographic areas and because those affected by the disease in less populated areas feel that they must keep it secret.

Thought to be a problem of the big city, AIDS doesn't fit in with the heartland's conventional self-perception. But HIV/AIDS is here, now, and the longer the epidemic drags on the more undeniable that fact becomes. In the Midwestern state in which I live, Indiana, one half of all the reported AIDS cases live in towns with populations under 30,000 or in rural areas (Rural Prevention Center, 1994).

Some issues encountered in the delivery of mental health services to those living in smaller communities are unique. Others represent variations on themes encountered in urban areas. But the issues encountered in rural areas are no less complex than those encountered in the largest cities. While the absolute numbers of cases may be fewer, other circumstances make HIV/AIDS-related mental health care in less populated areas complex and challenging.

When considering mental health service delivery in non-urban America, keep in mind that small towns and rural communities suffer as much from stereotyping as do any other segments of our society. Remark-
able diversity resides within these communities, making generalizations misleading and even dangerous.

**Background Reading**

Research and professional writing concerning the impact of HIV/AIDS on small town and rural areas has been scarce. This can partially be explained by the delayed expansion of the epidemic into rural areas, the secrecy surrounding the occurrence of cases, and the overwhelming spread of the disease and its impact on urban areas. The relatively higher concentration of research and professional resources found in urban centers has also led to greater research interest in HIV disease in those areas.

To have a literature to review, it was necessary to include material relating to health service delivery in general as well as mental health care specifically. Many of the issues encountered in rural mental health care are also common to other areas of health service delivery, for example, the availability of hospice care and home health care. Material specific to mental health care delivery in rural areas is scant. The majority of the health service literature devoted to HIV/AIDS in nonurban America makes only indirect reference to mental health services. The situation mirrors the inattention to health and mental health services for those with HIV/AIDS in small towns and rural areas.

For ease of presentation, the literature will be divided into four general areas: general policy and public health, service provider preparation, rural practice, and homophobia.

**General Policy and Public Health**

Articles in newsletters targeting health care audiences have pointed to the dramatic increase in the number of AIDS cases in small towns and rural areas (American Health Consultants, 1995; Hearn, 1994; Rural Prevention Center, 1994). Quoting findings from the National Commission on AIDS, the *Rural Prevention Report* (1994) noted that in 1989 the number of AIDS cases in rural areas increased 37 percent while the case increase in urban areas was 5 percent for the same year. American Health Consultants (1995) reported that data from studies on opportunistic infections, controlling for the 1993 change in the definition of AIDS, revealed that between 1989 and 1994 the percentage increase in AIDS cases among rural men infected through sexual contact with other men increased by 69
percent, while the percentage increase for those in the same risk category in urban areas was 19 percent. (See also Graham, Forrester, Wysong, Rosenthal, & James, 1995.)

These articles also point out that HIV disease is highly stigmatized in rural areas and note the relative inadequacy of health care resources in those areas. With health care resources already strained and rural areas underserved, health care providers are anxious about taking on new challenges. Stigma by association with HIV disease only adds another barrier to an already overburdened and uncertain future.

One of the most potent and revealing contributions to the literature is Vergheses' (1994) *My Own Country*. Written by a physician practicing in East Tennessee, this memoir vividly conveys the human suffering occasioned by the shame, guilt, and isolation produced by community reaction to the disease.

Articles tracing the epidemiology and the geography of AIDS have provided interesting insights into the spread of the disease. In an *Atlantic Monthly* article, Gould and Kabel (1993) described computer-assisted math modeling that traced the diffusion of AIDS across Ohio. Their research documented that in terms of geography, AIDS spreads in exactly the same manner as other sexually transmitted diseases, from urban areas outward and along the interstate highway system.

Research in the demography and the epidemiology of AIDS in rural areas has focused on documenting trends in the progression of the epidemic and tracking the effects of migration of individuals living with HIV disease from urban to rural areas in the Southeastern states (Davis & Stapleton, 1991; Rumley, Shapley, Waiver, & Esinhart, 1991; Whyte & Wilber, 1992). Researchers have been particularly concerned about an underestimate of AIDS cases in rural areas. This underestimate occurred because national prevalence statistics for AIDS do not take into account the mobile nature of our society and the underreporting of AIDS cases.

Researchers are concerned about whether the limited health care resources available in rural areas will be equal to the task of caring for an influx of AIDS patients, first diagnosed in urban areas, who return home to nonurban areas to be cared for through the final stages of their illness. Since federal funding for HIV/AIDS care has been tied to prevalence reports, urban areas have received the lion's share of funding, with medium and low impact states receiving little assistance.

One study (Wasser, Gwinn, & Fleming, 1993) focused on urban and nonurban women of childbearing age. Rates of HIV infection for these
women ranged from 0 to 12.2 per 1,000 population. Rates were highest in East Coast urban areas, but high rates were also found in nonurban areas, especially in the South. Incidents of HIV infection were three to thirty-five times higher for black women than for white women in nine states, regardless of urbanicity. Research such as this indicates that the complexion of HIV/AIDS in nonurban areas is multifaceted, adding to the service delivery challenge posed there.

Two policy papers have been generated by the Health Resources and Services Administration (HRSA) (Berry, McKinney, McClain, & Valero-Figueira, 1995; Health Resource and Services Administration, 1991). The first reports on four case studies, commissioned by HRSA, of rural areas in the South Atlantic and the Mountain census divisions. The study identifies issues important to the development of HIV services in nonurban areas. These issues are identified as the perception among rural residents that HIV is an urban problem; efforts at professional education that do not reach rural health care providers; the fact that HIV disease in rural areas is only one component of a more complex set of problems related to poverty, alcohol and drug abuse, and sexually transmitted diseases; and the need for government-supported research and development concerning health services for persons with HIV/AIDS in nonurban areas.

The second paper focuses on a series of five broad recommendations for public policy initiatives in the area of HIV education and service delivery: information needs; planning, coordination, and resource allocation; training and skill development; dissemination; and financing. The paper calls attention to the diversity of nonurban areas and to differences among special populations within those areas. While attention is paid to differences between urban and rural populations, significantly less interest is shown in the diversity found in nonurban areas.

**Service Provider Preparation**

Three studies relevant to mental health service provider training and preparation are worth mention. Two studies (D'Augelli, 1989; Pollard & D'Augelli, 1989) focused on knowledge, attitudes toward AIDS, and attitudes toward gays and lesbians. The first of these studied rural nurses and the second, rural volunteers in an AIDS prevention program. Results indicated that nurses had a great deal of knowledge about AIDS but unrealistic fears regarding transmission. One third of the nurses held
strongly negative attitudes toward homosexuality. This attitude decreased when they reported knowing a gay man. The incidence of AIDS phobia and that of homophobia were correlated.

The volunteers in the second study (Pollard & D’Augelli, 1989) demonstrated a relatively high level of knowledge about AIDS, but a large majority rated their knowledge as inadequate. Participants were not particularly worried about contracting AIDS. Attitudes toward homosexuals were either mixed or negative. Once again, fear of AIDS was correlated with homophobia. The authors concluded that quality of care may be compromised if caregivers’ negative attitudes toward gay individuals are not remedied. Specifically, they called for the inclusion of information regarding psychosocial and attitudes toward homosexuals as part of HIV/AIDS training.

Aruffo, Thompson, Gottlieb, and Dobbins (1995) reported on the effects of training on a group of mental health service providers in rural Arkansas. Results of pre- and posttests showed that training effects were positive, and the authors concluded that training is important for developing a knowledgeable and accessible base of mental health service providers in rural areas.

**Rural Practice**

The rural practice literature relating to HIV/AIDS, though limited, is dominated by the work of Kathleen Rounds. Her article (Rounds, 1988a) reports a qualitative study of care providers working in rural areas and contains an excellent overview of issues encountered by health and human service providers as they attempt to care for those with HIV/AIDS. Findings of the study were categorized under the headings: structural (including geographical distance), concerns for client confidentiality, fear of AIDS contagion, and homophobia. She concludes with a number of suggestions specific to the development of HIV services that should serve to enhance service delivery.

The guidance offered in this study and in a companion article (Rounds, 1988b) concerning community development work in rural areas is especially worth a serious reading. The author notes, among other things, that community development work in nonurban areas follows informal networks of personal and professional relationships. She advocates the use of these networks in building HIV/AIDS service delivery systems.

Rounds, Galinsky, and Stevens (1991) reported on a unique approach
to HIV support groups tailored to rural areas. They established a telephone support group for HIV-infected individuals. The article reports on the protocol for the development of the group and the results of a pilot group. The group offered a unique and interesting approach to outreach to individuals who might never attend a conventional support group, either because of distance or because of fears concerning confidentiality.

Fuszard, Sowell, Hoff, and Waters (1991) reported results of a national study of rural American hospitals and their readiness to care for HIV/AIDS patients. While the vast majority of hospitals had acute-care services in place and had educated employees about universal precautions, the study found that other services were lacking. Community services were basically unavailable in rural areas, as were many other patient care services. Unavailable services specific to HIV care included adequate discharge planning, chronic care, and patient and family education services.

Seeley, Wagner, Mulemwa, Kengeya-Kayondo, and Mulder (1991) reported on the development of community-based HIV/AIDS counseling services in rural Uganda. While the focus of the present chapter is on nonurban America, the Ugandan experience is instructive and noteworthy if for no other reason than that it is one of the few articles in the professional literature that deals primarily with mental health services and HIV/AIDS in rural areas. The authors relate their experience in making entry into two separate rural communities. Lessons learned regarding community development in Uganda only serve to reinforce those reported by Rounds (1988a, 1988b). These authors also look at counseling models developed primarily in Europe and America and conclude that these models must be adapted to African culture by placing greater emphasis on family support.

Homophobia

Various authors have researched and written about the interrelationship of AIDS phobia and homophobia. Others have written about the pervasive nature of homophobia, especially in small-town and rural areas (D’Augelli, 1989; Pollard & D’Augelli, 1989). It is beyond the scope of this chapter to review that extensive literature. Suffice it to say, however, that the homophobia associated with HIV/AIDS has a powerful and multifaceted impact on the availability of health and human services in nonurban areas, the quality of care given when these services are available, and the patterns of help-seeking behavior in which those living with HIV disease engage.
My Clinical Work

I write after more than a decade of labor in HIV service delivery, in settings that varied from large urban centers to medium-size cities to small-town and rural areas.

In 1991 and 1992 I received funding for two independent but interrelated projects that serve as the experiential basis for this chapter: the Indiana Integration of Care Project and the Heartland Care Center. Both projects have provided a wealth of experience in mental health service delivery across an essentially nonurban Midwestern state.

The purpose of the integration project was to demonstrate the integration of community-based mental health services into the primary health care of the HIV-infected across the state of Indiana. The project consisted of four components: referral network building, integration into existing health and human service systems, training and support for mental health service providers, and research and project evaluation. Although the project was not conceived to target rural areas specifically, in point of fact, half the AIDS cases reported in Indiana are in nonurban areas. The past five years of training, consultation, and network building across the state have provided a considerable fund of experience regarding HIV mental health service delivery and community development.

Coincidental with the development of the integration project, the Heartland Care Center came into being. It is one of twelve state-supported HIV-dedicated care coordination centers in Indiana and serves an essentially rural area composed of seven counties in west-central Indiana. It is housed on the campus of Indiana State University and offers care coordination, counseling and testing, support groups, and individual and couples counseling to the HIV-affected in the Wabash Valley.

Heartland Care Center is unique in Indiana in that it is located on the campus of a state university and graduate students in the Department of Counseling, working under faculty supervision, provide services to clients. Thus it has a training function, for both students and faculty supervisors, in addition to that of service delivery.

The observations and lessons in this chapter have been the outgrowth of these two projects.

Barriers to HIV/AIDS Service Delivery in Rural Areas

Two barriers to care for HIV/AIDS are the most salient in nonurban and rural areas:
1. Geography. This is the most obvious barrier, both for those with HIV disease and for those who attempt to respond to their needs in nonurban areas. The essential problem is the broad spread of HIV cases over a large geographic area. The relatively thin spread probably does not justify the development of HIV-dedicated services within specific communities, so the task becomes one of integrating HIV services into existing community-based health and human service agencies.

Existing agencies are typically already stretched beyond their capacities. The addition of services targeting those living with HIV disease, along with the attendant stigma, is not a welcome development to service providers.

Nonurban geography insulates service providers, who consequently tend to view AIDS as not something that affects their communities. Little importance is attached to development of HIV services. Given the best of motives, nonurban service providers are not likely to have encountered many HIV-affected individuals requesting care. Thus, considering other problems that press for attention, they are unlikely to see as a priority the development of HIV services or training that would increase their competence in this area. In fact, they often see planning and training efforts as punishment because they detract from more pressing issues.

2. Homophobia. From the beginning of the epidemic in America, AIDS has been labeled the “gay plague.” A minister who was one of the first transfusion-related AIDS cases and who lived in Indiana said toward the end of his life, “The issue is homophobia pure and simple.” He continued, “I never had any conception of what it was like before I became infected. Once infected, I was tarred with the same brush of homophobia that tars the gay man who is HIV infected.”

Recommendations for Future Practice

While geography forms a barrier to providing care to those with HIV disease in nonurban areas, it can be overcome.

Emphasis should be placed on regional centers for the development of HIV services. Most small-town and rural areas have a larger town or small city as their geographic focus for retail trade, entertainment, and medical care. These regional centers may serve as focal points for the development of HIV services that can serve larger geographic areas. (Note
that these regional areas do not necessarily follow state boundaries.) Since a proportionately larger number of HIV cases can be expected in these regional trading and medical centers, the development of HIV services there would make greater economic sense. These regional centers frequently also have institutions of higher education and medical residency programs associated with hospitals. Medical educators and faculty in regional colleges and universities are often more approachable regarding development of HIV services in their geographic area and may even be counted on to provide leadership for service delivery planning and development.

In most instances, leadership for HIV community-based resource development and maintenance will have to come from outside the specific small town or rural area. The regional centers are ideally positioned to bridge the gap between federal and state-level resources and the needs and realities of the local nonurban area. A focal point for sustained leadership, such as a regional care center, is critical to the establishment and integration of HIV service delivery in nonurban settings.

Development of telephone and computer-based “warm lines” for case consultation can assist mental health and other health and human service providers by providing needed information, guidance, and support. But such technology-assisted resources will be used only to the extent that they emerge out of trusting relationships between professionals. This is especially true in the area of mental health care. Those staffing “warm lines” must have a great deal of credibility and demonstrated skill in the area of HIV service delivery and mental health. They must also possess excellent training, supervision, and consultation skills. Periodic field visits are necessary to reinforce relationships with mental health professionals who utilize these support services.

**Tools for Clinical Practice**

I have found these points to be critical in developing a system for HIV/AIDS services delivery in nonurban areas:

- *The importance of the community-level sanctioning process cannot be overstated in the development of HIV services in small towns and rural areas.*

  Rounds (1988a) and Seeley et al. (1991) have pointed out the importance of informal social networks for providing support and care in nonurban areas. Experience bears this out. People in
small towns and in rural areas typically have different expectations regarding caregiving, founded in an ethic of self-reliance and a deep-seated distrust of government. People are expected to take care of themselves and their own, and reliance on outside organizations can be construed as a failure of self-reliance, the family, and community.

Different approaches are required, therefore, in making entry into nonurban communities and developing HIV-related services (Rounds, 1988b). Formal organization and public meetings with accompanying media coverage should be eschewed in the beginning because they provide opportunity for the venting of reactionary opposition. More efficient entrance can be made by using naturally existing informal support networks and working through one supportive individual at a time. These individuals who live within the local community can then provide leads to others who might be supportive or have resources. This “snowball” approach to community resource development is slow but has the advantage of allowing for the development of a network of service providers and resources in a nurtured and relatively safe environment. Once a sufficient number of people has become involved to give a certain amount of community sanction to HIV service delivery, a more public approach can be taken.

With service providers afraid for their reputations and their practices should it become known that they are the “AIDS Doc” or the “AIDS mental health service provider,” it is essential that they know that there is a segment of the community who will support them. It takes an unusually strong individual to buck public sentiment in a rural area, where the economic and personal consequences for running counter to public opinion can be grievous. Those individuals who do run this risk are often motivated by deeply held moral and religious beliefs. Religious sentiment, however, in a local community is more likely to be dominated by fundamentalistic Protestantism and may be strong enough to inhibit such individuals from action on the HIV front.

- **When networks of service providers are established in small towns and rural areas, they are likely to be thinly staffed and very fragile.**

A whole service delivery network in a rural area may depend on one concerned professional or lay person. If that person leaves or becomes ill, the network falls into crisis. Maintenance becomes
a constant issue and can be difficult, given the far-flung geographic spread of the service delivery system.

Similarly, a disruptive client can damage a fragile delivery system. Too often, once a client has been diagnosed with HIV disease, everything else about the client recedes into the background; service providers focus on the HIV to the exclusion of everything that has gone before. But many individuals who become HIV-infected have had multiple problems before infection. The HIV diagnosis is simply another overwhelming stress, and they may not have particularly good coping skills.

Service providers' immediate reaction to such disruptive clients is often a decision, based on one experience, that all HIV clients are impossible to treat, and they terminate their participation in the service delivery network.

A great deal of effort and leadership is required to support the network and to ensure its viability. The mind-set of those developing HIV services in small towns and rural areas can only be one of long-term effort working toward long-term goals.

- Many people in rural areas have negative attitudes regarding mental health services.

Mental illness still carries a great stigma of its own, and this stigma is readily apparent in many rural areas. An attitude exists within much of the population that leads people to believe that mental health care is for "crazy people." Similarly, a person with HIV/AIDS may view his or her situation as strictly one of physical illness and reject mental health care as inappropriate. Physicians frequently make mental health referrals only as "referrals of last resort" and may present such referrals to difficult patients as the alternative unless they become more compliant.

- HIV/AIDS mental health care and health service delivery in nonurban areas is an exercise in multiculturalism.

While much of multicultural education encountered in the graduate training of mental health care providers focuses on issues of gender and race, experience in small-town and rural areas leads us to believe that such a definition of multiculturalism in not nearly broad enough. Certainly multiculturalism in rural America can be illustrated by, for example, the presence of large numbers of racial-ethnic minorities such as African Americans and Hispanics in given localities. But another example of cultural
diversity is the presence of migrant farm workers, which represents a very mobile population. Some nonurban areas are populated by religious sects such as the Amish. The mental health provider needs to take these cultural and community differences into account in planning and delivering services.

- **Confidentiality, difficult to maintain in small towns and rural areas, creates paradoxes of service seeking.**

  It is practically impossible not to know people through multiple contacts and in multiple roles. It is not uncommon for the receptionist at the doctor’s office to be someone with whom the client went to high school. News travels quickly, since there are fewer people to engage in the process of dissemination.

  HIV clients have reason to be concerned about confidentiality. Jobs are still lost, families still disintegrate, homes are still given up, insurance can still be lost because of breaches in confidentiality. Some of those living with HIV disease still have their homes burned when their HIV status is revealed.

  Conversely, for those living with HIV disease in small-town and rural areas, geographical distance may spell assurance of confidentiality, and herein lies a paradox: While the client is asymptomatic and service delivery needs are the least complex, services are typically sought at a distance. When the client becomes more symptomatic, gets too sick to travel, and needs the most experienced care, services are sought locally. Yet, services available locally may not be adequate to the need. HIV service delivery planning for nonurban areas needs to take this pattern of service seeking into account.

- **The development of integrated health service delivery for those living with HIV/AIDS depends on the cultivation of relationships not only within individual systems, e.g., mental health centers, hospitals, and HIV/AIDS dedicated social service agencies, but also between agencies, care providers, and informal support networks.**

  The provider in a nonurban setting cannot afford to sit comfortably in an office and only provide services. That person must be a networker. That means the devotion of constant attention to the informal network of personal relationships in terms of case finding, service delivery, and referral resource development.

- **Distance and lack of transportation are barriers to accessing care.**

  Although fairly obvious, this is often lost on discharge plan-
ners in large, urban, tertiary-care hospitals. Hospital staff need to work closely with community-based care providers to determine if plans for follow-up care are possible, much less probable. The realities of nonurban life and the distance between available sources of needed care may impose severe limits on such plans.

- **The darker side to the often laudable and proud tradition of “taking care of our own” in small towns and rural areas is the relatively narrow definition regarding who is deserving of care.**

  By and large, gay men and injection drug users do not fit into this category. Issues of social class and race may also bear on this question. Typically, small towns and rural areas export nonconventional individuals to urban areas, and, of course, many are uncomfortable with the conformity espoused by local communities. Given this, small-town or rural communities can pretend that these kinds of differences do not exist. And, of course, if there are no gay individuals, for example, living within the community for the local population to know, there is no reason for their stereotypes to be dispelled. The mental health provider can respond by advocating tolerance if not acceptance of these individuals. Mental health service providers already enjoy some degree of social sanction for advocating unpopular causes. This social sanction can be capitalized on to broaden the boundaries of community acceptance.

- **Infected gay men coming home to die is a scene repeated daily across the small towns and rural communities of America.**

  Such homecomings are fraught with difficulties. In many cases the offspring’s homosexuality was never openly acknowledged in the family or community. The family must thus cope with the conscious knowledge that a member is gay and that he is dying. Often the original leave-taking was not accomplished under the best of circumstances, and much unfinished business has been left incomplete. The return home tends to reactivate these old and perhaps festering issues. Fractures often appear in the marriage of the parents as they attempt to cope with this situation.

  Such homecomings may have a very high cost attached. Experience indicates that sometimes families agree to take their offspring back and provide care through the final illness only if he or she agree not to have contact with any gay or lesbian friends. In more extreme cases, the HIV-infected person is asked to
renounce his or her sexual orientation. Religious rites of reconversion may also be a part of the bargain.

The mental health provider involved in this situation is faced with ameliorating the crisis that such a homecoming produces. At the same time, opportunity may exist within the destabilized family system to make significant impact on long-standing and maladaptive patterns of interrelating.

- **Homophobia is more likely to be internalized within gay and bisexual individuals who remain in small towns.**

Certainly, the manifestations of internalized homophobia are easier to spot in the lives of gay and bisexual men who are HIV-infected and who have lived most of their lives in rural areas. Internalized homophobia can be found in the number of gay and bisexual men in heterosexual marriages, the understanding of their own sexual orientation in terms limited to sexual activity, reluctance to seek HIV testing and treatment even when they know they are infected, and the amount and pervasiveness of religious guilt present, especially during the final stages of the disease.

One outcome of this internalized homophobia is the number of multiple infections found in single families. Wives and newborn infants thus end up paying the price for this endemic homophobia. Internalized homophobia also affects men of color who have sex with other men. It is not uncommon to find these men claiming infection through injection drug use, when in fact they have never engaged in needle sharing and simply find admitting to injecting preferable to homophobic stigmatization.

Internalized homophobia makes for difficulty in accessing those who are in need of services, slow going in counseling and psychotherapy, and complicated ethical problems. Closeted clients may not be willing to come for services to a service center that is identified with caring for the HIV-infected. In some cases, it may be necessary to meet them on their own turf, at least initially. Complicated ethical issues present themselves when individuals fail to warn partners that they are HIV-positive, potentially putting them at risk.

- **Institutional manifestations of homophobia in nonurban areas run the gamut from denial of hospital visiting privileges to lovers to denial of access to services altogether.**
A particularly interesting twist on institutionalized homophobia is the referral of gay and lesbian clients to openly gay and lesbian service providers in mental health centers. This phenomenon also exists in private practice but is not as prevalent in nonurban areas.

On the one hand, this practice can ensure that gay clients are matched with professionals who may have a vital interest in HIV service delivery. On the other hand, as long as HIV clients can be referred to specific professionals on the basis of sexual orientation, other professionals do not have to become knowledgeable or explore their own negative attitudes that may form barriers to accessing care.

- Because nonurban areas are generally underserved, mental health care providers working with HIV/AIDS clients often have to play multiple roles and serve multiple functions for the client.

It may be necessary for the mental health service provider, lacking other resources, to act as informal monitor of the quality of medical care that the client receives or as client advocate for access to housing or other social services necessary for the maintenance of well-being. This role overlap can be confusing for the client as well as for the mental health service provider. It also assumes that the service provider has a knowledge base sufficient to know when to question the quality of care an HIV/AIDS client may be receiving from another professional. Interpersonal tact is also necessary in large measures to perform this role while still maintaining relationships with other professionals who are providing care to the client.

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